October 1, 2024 Volume V.I



K's KolumnLong Time Coming



It has certainly been that, in more than a couple of ways. Let me start by saying I have missed each of you over the last five plus years. In that time we have seen a government shutdown, a super blue blood moon, historic midterm elections and a very American addition to the British royal family, and all that was in 2018. Don't forget about Notre-Dame de Paris, catching fire and the third president in U.S. history to be impeached in 2019, Covid-19, was the big story in 2020, and the vaccine as well as Brandon Brown winning the Sparks 300 race at Talladega in October. Many more things have happen in the last three years including my Mulitivisceral Transplant in March of this year..

I have been seen at several hospitals in this time also. Sepsis, Covid, dehydration, malnutrition, and a myriad of other diagnosis have kept my doctors and I searching for alternative ways to keep me going. After a visit to the hospital in the Spring of 2023, my primary doctor and I came to the conclusion that it was time to seriously consider the transplant route again.

So it began, the selection process for another transplant doctor. I did my due diligence in researching and finding the best program for me. I finally decided on the team at Indiana University in Indianapolis and Dr. Mangus. He is the former partner of Dr. Tector, the doctor that was going to do my transplant at UAB before the program was shutdown and he moved on to Miami.

I had my transplant on Good Friday, March 29, 2024. While doing an interview with Rick Karle, a few days after surgery, for his <u>Rick Karle Good News</u> Facebook group, I realized the true symbolism of my transplant as I got out of bed for the first time post-transplant on Sunday morning, Easter Sunday. This proved to me that this was truly a God thing, as only He could have worked all these miracles to heal me.

This helped us to live through Daniel 4:35, "All things in heaven and on earth are under God's control." Therefore, we lived with the peace and knowledge that everything was going to be okay. Now that we are back home, we are continuing live this as we make doctor's visits nearly everyday and travel back and forth to Indiana monthly. Knowing this alerts us to be consistent and focused on things at hand and not trying to do more than is obtainable by a single person. Again, thank you for your assistance, we would not be here without you.

October 1, 2024 Volume V.I

What to know ...

Intestinal (IT) and multivisceral transplantation (MVT) is a surgery that removes diseased or malfunctioning organs along the gastrointestinal tract and replaces them with healthy donor organs.

Key Facts about IT and MVT

- Can be used to treat a variety of conditions.
- Certain conditions that lead to intestinal failure may also cause liver failure,
- Frequently associated with liver transplants.

Purpose

IT and MVT are performed in people with severe gastrointestinal (GI) conditions that cannot be treated any other way. The GI tract refers to the group of organs that make up the digestive system.

Types of IT and MVT

Depending on the condition, there are several types of transplantation surgeries to replace the organs of the GI tract:

- **Isolated IT (Small Bowel Transplant (ISB))**: involves removing the diseased portion of the small intestine and replacing it with a healthy small intestine from a donor.
- MVT: this may be considered for patients who have multiple organ failure.
- Modified Multivisceral Transplantation (mMVT): this may be considered for patients who do not have liver disease/failure, but have organ failure.

Conditions

The following are some of the most common conditions that can make IT and MVT necessary. :

- Blocked or obstructed intestines (atresia)
- Crohn's disease
- Endocrine tumors
- Hirschsprung's disease
- Multiple resections and explorations
- Severe cholestasis induced by total parental nutrition (TPN-IC)
- Vascular abdominal trauma

Many of these conditions are congenital, which means they are present at birth. Because of this, IT and MVT surgeries are most often done on very young children.

Procedure

The various forms of IT and MVT all involve the removal of donor organs, the removal of the diseased organs, and the implantation of the donor organs. Successfully implanting the donor organs requires the surgeon to reestablish all of their veins, arteries, bile ducts, and other vital connections. The entire process will usually take 8 to 12 hours to complete.

The following is the general step-by-step process of an IT or MVT:

- 1. **Preparation**: When a patient is matched with donor organs, the transplantation operation will begin as soon as possible.
- 2. **Anesthesia**: This will put the patient into a deep sleep for the entirety of the operation.
- 3. **Incision**: A long incision across the abdomen to gain access to the organs.
- 4. **Evaluation**: The diseased organs are evaluated for any abnormalities that would prevent a transplantation.
- 5. **Removal**: All existing connections are severed from the diseased organs.
- 6. **Implantation**: The donor organs are implanted inside the patient.
- 7. **Closure**: When all bleeding is controlled, the surgeon sews the incision closed.

October 1, 2024 Volume V.I

The following are some of the types of doctors that may be involved in an IT and/or MVT:

- **Gastroenterologist**: A specialist in diseases of the digestive system.
- Transplant Hepatologist: A specialist in the liver, pancreas, and gallbladder.
- Transplant Surgeon: A specialist in removing and implanting organs.
- **Anesthesiologist**: A specialist in administering sedatives and anesthetics.
- **Radiologist**: A specialist in imaging organs.

Alternatives

Currently, few alternatives to intestinal and/or multivisceral transplantation exist. While some medications and therapies may be able to delay organ failure or alleviate symptoms, surgery is usually the only viable way to treat gastrointestinal conditions of this severity.

Risks and Complications

IT and MVT are extremely complex operations, which means they come with significant risks. The most common complications include postoperative hemorrhage, vascular leaks or obstruction, and biliary leaks or obstruction.

The following are some other risks associated with IT and MVT:

- Bile leaks
- Depression or anxiety
- Donated organ failure or rejection
- Increased risk of skin and certain other cancers
- Infection (Sepsis)
- Internal bleeding
- Intestinal leaks (Leaky Gut)
- Vascular complications

What to Expect Afterwards

IT and MVT can be a life-saving procedure. However, as complex operations, patients may experience a range of outcomes and recovery times depending on the organs transplanted, the severity of their conditions, and their overall health. All patients will also likely have to take some form of medication for the rest of their lives.

Recovery

Typically, patients remain hospitalized for several weeks after surgery. During this time, their transplant team will evaluate them for any signs of possible complications and assist with the recovery process, such as by providing proper nutrition and exercise routines. Afterwards, they can return home to recuperate. This process can take several months to over a year.

Medications

Patients will have to take a variety of medications after their surgery, some for the rest of their lives. In general, these medications can be divided into three categories:

- **Anti-Rejection**: Also called immunosuppressants, these medications weaken the immune system so that it does not reject the new organs.
- **Anti-Infective**: Because the immunosuppressants weaken the immune system, patients will need to take anti-infective medicine to protect against infection.
- **Miscellaneous**: Additional medications may include ones to treat the side effects of the immunosuppressants or help with other medical conditions.

Hey Buddy, Can You Spare A Penny?

We would like to express our deepest gratitude for your generous contributions towards "Keep Kirsten Kicking". Your contributions of time, prayer, money, physicality, or any other of your many talents have assisted in relieving the growing burden of expenses involved with the care needed to continue moving forward. If you are considering a year end donation then, we would like to ask for you to consider making a tax deductible donation to Southeast Transplant Fund in honor of Kirsten Steele for the care that she desperately needs.

In case you are not familiar with Kirsten's story, we want to share some of the highlights with you. Several years ago she started experiencing constant nausea and vomiting. After a few years of doctor and hospital visits, she was diagnosed with two rare life-threatening digestive conditions, <u>Chronic Intestinal Pseudo-Obstruction</u> and <u>Gastroparesis</u>. There are many reasons these conditions may occur, but typically they are caused when the muscles of the stomach and intestines do not function properly resulting in food moving slowly or stops moving through the digestive tract.

Your support is needed now, more than ever. Please take a few minutes and go to our <u>campaigne page</u> where you can help by making a tax-deductible donation to Help Hope Live in honor of Kirsten. Once there please follow the prompts to choose which gift you will give and the impact you will make. If you'd prefer to send your gift by mail, please send it to Help Hope Live, 2 Radnor Corporate Center, Suite 100, 100 Matsonford Road, Radnor, PA 19087. Please be sure to write "in honor of Kirsten Steele" on the memo line.

Your continued support and contributions are greatly welcomed and drastically warranted. Your gift of \$50 will assist us in our long-term travel to see the team in Indianapolis, \$25 will help with one day's meal plan for us while traveling; and \$10 will cover other fees incurred; including home medical equipment and supplies, insurance premiums, co-pays and deductibles, and many other area items that will be beneficial to us. If you do not have the capability of gifting monetarily, that is okay; we can use any of your non- economical (spiritual, social, personal, or in-kind) donations will be greatly appreciated and benefit us in a way you would never imagine.

We thank you again for your assistance, support and compassion as we move forward in this process. We look forward to keeping you updated on our journey to a "new normal".

Sincerely,

Robert & Kirsten Steele

Upcoming Planned and Proposed Event

Fall 2024	Winter 2025	Spring 2025	Summer 2025
Softball Tournament	Super Days Ahead	Golf Tournament	Nonprofit Day
Giving Tuesday	NCAA '25	Donate Life Day	World SB Day
College Football Bowl Pick'em	Donor Day	Hope In Action	Cure The Runs (5K)



Help Hope Live is the nonprofit organization that we have joined forces with for our fundraising opportunities. Their mission is to support community-based fundraising for people with unmet medical expenses and related costs due to cell and organ transplants or catastrophic injuries and illnesses. Please help us celebrate the hard work they do to benefit all the people they help.